

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 226. Summer 2024

Ataxia UK Roadshows Coming to...

Belfast

Thurs 20th June



&

Edinburgh

Sat 22nd June



- Ataxia people • Research • Ataxia awareness
- Health & wellbeing • Fundraising
- Living with ataxia • Services

ATAXIA

Ataxia UK

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CEO's introduction

The optimism of spring brings hopefulness, and our hope for treatments and cures for this generation of people affected by ataxia remains strong – buoyed up by the recent decisions of the European Medicines Agency. In February they approved Skyclarys® for use in adults with Friedreich's ataxia (FA) in Europe, and recently started consideration of Troriluzole for use in SCA3 (Spinocerebellar ataxia type 3). We have actively represented the views of patients to the EMA (European Medicines Agency) in each of these processes. Although since Brexit, European approvals no longer directly affect the UK; the British Government has introduced a new fast-track approval process for treatments approved in the US, Canada, Singapore, and Europe – so hopefully Skyclarys® and Troriluzole will, once submitted, become quickly available in the UK (See p8 & p6).

We've come together for the first of three roadshows in Cardiff in late April, and I'm pleased to inform you that it was a great success. The team is now working hard and looking forward to the remaining two events in Belfast on the 20th of June and Edinburgh on the 22nd of June. There's still time to book your tickets, but hurry as the bookings close on 12th June. We hope to see lots of you at these events for an interesting day, considering not just the lows of an ataxia diagnosis, but also reflections on how engaging and fulfilling life can be despite it (See p4).

Finally, for those of you who enjoy meetings and want to give an extra commitment to Ataxia UK, please will you consider whether you have the time, skills, and attributes to become an Ataxia UK Trustee. To apply today, see p5 for more information.

Best wishes,

Sue Millman



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Ataxia UK Roadshows

Ataxia UK is coming to you! We're continuing our roadtrip across the UK, visiting the capital cities of the devolved nations.

Our first Roadshow event in Cardiff was a resounding success: *'Very informative and welcoming. My friend was a bit worried coming to this event but quickly felt at ease. Brilliant.'* – **Cardiff event delegate.**

There's still time to attend one of our other two events. Both roadshows include 'It Works For Me' talks from Ataxia Friends, research updates, a Doctor's Q&A, a presentation from the Chief Executive of Ataxia UK and interactive breakout sessions, as well as talks tailored to each location.

BELFAST. Thurs 20th June. The Hilton Hotel, Belfast. 10:30am-4:30pm

- Doctors Q&A with Dr John McKinley (Royal Victoria Hospital, Belfast)
- Neurophysiotherapy breakout session
- A talk from Finola McGrady about the implementation of the UK Rare Disease framework in Northern Ireland

EDINBURGH. Sat 22nd June. Novotel, Edinburgh Park. 10:30am-4:30pm

- Hosted by Paul Coia
- Doctors Q&A with Dr Rajith De Silva
- One-to-one advocacy advice sessions with Eilidh Clarke (Parkhead Citizen's Advice Bureau) who provides our Scottish Advice Service.
- A talk from Natalie Frankish from Genetic Alliance UK on the latest policy updates and cross-border referral issues
- and more to be confirmed!

BOOKING

You can find out more about the Roadshow events, including programme for each location, and book your tickets at <http://alturl.com/hnpv3> Tickets cost £34.00 and include lunch and refreshments. Bursaries are available for those on means tested benefits.

ATAXIA UK VIRTUAL ANNUAL CONFERENCE 2024 - SAVE THE DATE! Fri 27th & Sat 28th September

This year's Annual Conference will be taking place online, hosted by Paul Coia and featuring a jam-packed programme brought directly to you in the comfort of your own home! Keep an eye on our social media, newsletters and the next magazine for more information.

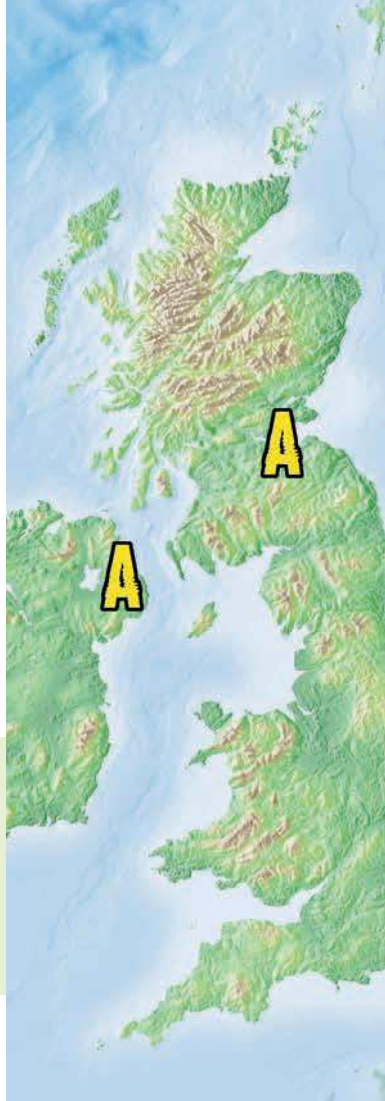
Friday 27th September afternoon – Research day

- Research Updates • Doctors Q&A

Saturday 28th September – Main day

- It Works for Me talks • Key speaker • Breakout sessions • Much more

Register your interest today by heading over to our website: <http://alturl.com/upanm>



GET INVOLVED:

We're looking for people to do 10-minute 'It Works For Me' talks. These are always a popular feature of our conferences and involved Ataxia UK Friends sharing what works for them in managing the challenges of their ataxia. From handy gadgets, helpful mobility aids, an exciting hobby or learning a new skill, this is your chance to share your tips with fellow ataxians. You can do your talk live online or record it in advance. If you're interested in taking part, contact **Anastasia** at conference@ataxia.org.uk

Have you the vision, commitment, and experience to be a Trustee of Ataxia UK?

We have a vacancy on the board for one Trustee. We are seeking someone with professional experience in accountancy, fundraising, pharmaceuticals, the NHS, social care, or charity governance.

The elections take place in early September. A Trustee's term runs for 4 years, after which they can re-stand for a further term of 4 years. The Trustee Board governs and sets the strategic direction of Ataxia UK. Trustees oversee every aspect of Ataxia UK's operation, including finance, services we offer, the research we fund, and how we fundraise. It ensures that the charity is financially viable and has robust policies and procedures covering every area of our operation.

The Board meets 4-5 times a year mainly on Zoom and once a year face-to-face/hybrid. Meetings are from 11am – 3.30pm. Most Trustees also join a sub-group of the Board looking at finance, services, fundraising etc.

The Board is made up of Friends of Ataxia UK; seven who are elected by Friends of Ataxia UK and three who are appointed by the Board and co-opted. All prospective Board members are interviewed by two current Trustees prior to standing for election or being co-opted. We cover all costs incurred by Trustees in the course of their duties – including (when attending face-to-face meetings) those of a carer, if required.

We are keen to broaden the diversity of our board members to ensure we have a range of perspectives at meetings. We particularly encourage people who come from ethnic minority groups or are members of the LBGTQ+ community to apply for these roles. All Trustees are given an induction into the Trustee role and how the Board operates at Ataxia UK and offered opportunities for external training.

You can find more information including a Role Description by visiting www.ataxia.org.uk/work-for-us/trustee-jd Anyone interested will have the opportunity to attend an online information session with **Sue Millman, CEO** prior to interview. Please let **Lucy Porter, Executive Assistant**, know of your interest by emailing lporter@ataxia.org.uk You can also reach her via telephone on **0207 582 1444**.



EMA approves Skyclarys® for treatment of adults with FA in EU countries. What are the steps towards UK approval?

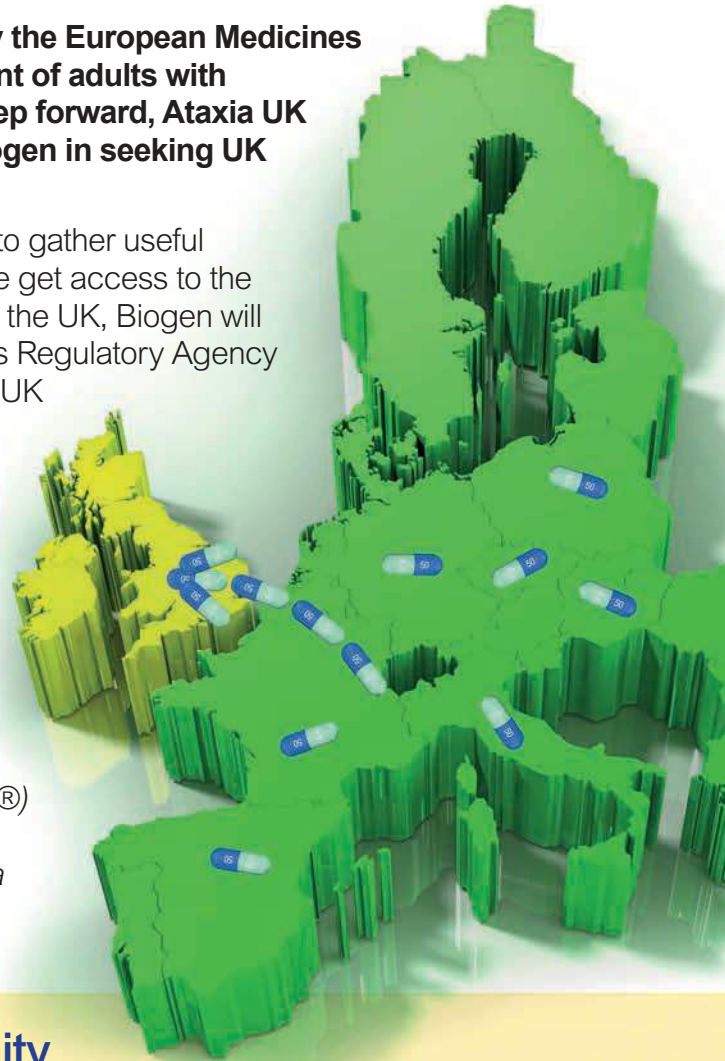
On 12th February 2024, the EU drug regulatory body the European Medicines Agency (EMA) approved Skyclarys® for the treatment of adults with Friedreich's ataxia (FA). Whilst this is an amazing step forward, Ataxia UK is making every effort to encourage and support Biogen in seeking UK regulatory approval.

In addition, we are discussing other ways to cooperate to gather useful information from people with FA in the UK to help people get access to the drug if it is approved. For Skyclarys® to be approved in the UK, Biogen will have to apply to the Medicines and Healthcare products Regulatory Agency (MHRA) - the body that regulates drug approvals in the UK - for regulatory approval.

The drug will need to go through the 'Health technology assessment' process, where decisions are made on funding of drugs within the NHS. We will ensure the FA community in the UK is kept up to date with the latest developments as soon as possible. The interests of families affected by FA, and all other types of ataxias, in the UK, are and will continue to be at the forefront of all our efforts.

You can find out more about Omaveloxolone (Skyclarys®) on our 'Omav Updates' website page here:

www.ataxia.org.uk/omav-updates We also distribute a newsletter on Omav updates, which you can sign up to through the same link.



Biohaven presents research on quality of life in SCA1, SCA2, SCA3 and SCA6

The pharmaceutical company Biohaven has conducted a research study on self-reported quality of life in those with SCA1, SCA2, SCA3 and SCA6, the results of which have been presented at four international research conferences.

Ataxia UK supported Biohaven in conducting the research. The research shows the significant impacts of impaired mobility and motor function on mental and physical wellbeing of those living with SCAs.

Biohaven made an application to the European Medicines Agency (EMA) for the approval of Troriluzole for the treatment of SCA3 in October 2023. Ataxia UK, via our work with Euro-ataxia, submitted a letter to the EMA highlighting the urgent need for treatments for people with SCA3, providing information on the burden of illness and asking for regulatory flexibility given the condition's rare nature.

You can read the research posters on the Biohaven website here: **<http://alturl.com/yepq3>**

Read about Biohaven's application to the EMA for the approval of Troriluzole for the treatment of SCA3 on our website here: **<http://alturl.com/nch8h>**

Positive update on the PTC Therapeutics drug, vatiquinone, for the treatment of FA in children and adults

On 29th February, PTC Therapeutics announced that they expect a potential New Drug Approval (NDA) submission for Vatiquinone for the treatment of FA in children and adults in late 2024, following a meeting with the US drug regulatory body, the Food and Drug Administration (FDA). This is based on the results of the placebo-controlled MOVE-FA trial, along with data from the ongoing open-label extension study. The drug is being investigated by the EU regulator, the EMA, with an expected outcome in the first quarter of 2024.

Read about the progress of the phase 3 clinical trials of vatiquinone for FA here: **<https://tinyurl.com/bdedsn5u>**

Voyager Therapeutics and Neurocrine Biosciences announce the selection of a lead candidate for their FA gene therapy program.

On 26th February, Voyager Therapeutics announced, that through their collaboration with Neurocrine Biosciences, they have selected a lead development candidate in their Friedreich's ataxia (FA) program. The candidate is a replacement for the mutated gene FXN (which codes for the frataxin protein) inside a shell called a capsid. In FA the mutated FTX gene causes a reduction in the frataxin protein which in turn causes the symptoms of FA. Replacement of the FXN gene with a non-mutated one should result in a restoration of frataxin protein levels. This candidate is part of the Voyager and Neurocrine capsid discovery platform TRACER™. TRACER-generated capsids have shown the ability to enter parts of the brain and central nervous system that are traditionally hard to reach.

The companies expect the FA program to advance into its first-in-human clinical trials in 2025.

Read the press release from Voyager here: **<http://alturl.com/p9kjf>**



Testing an experimental treatment for DRPLA and possible benefits for other rare ataxias

Ataxia UK started a partnership with CureDRPLA in March 2020 with the mission of advancing research for the very rare ataxia Dentatorubral-Pallidolusian Atrophy (DRPLA) and finding potential treatments.

With funding from CureDRPLA, Ataxia UK was able to employ a Research Manager, Dr Silvia Prades, to focus solely on the DRPLA programme. Earlier this year, we reached an important milestone towards the mission of finding potential treatments with the announcement of an upcoming experimental treatment for a person with DRPLA in the US. This is known as an 'n-of-1 clinical trial' because the trial is designed for a population of one person. *Read the announcement here: <http://alturl.com/8nmuv>*

This n-of-1 trial is being carried out by the n-Lorem Foundation, a non-profit organisation that charitably provides experimental antisense oligonucleotides (ASO) to treat people with rare diseases that affect very few people in the US. n-Lorem has an experimental ASO specific for DRPLA which could be a useful therapeutic approach if it succeeds in reducing the levels of the abnormal protein that accumulates in people with DRPLA. The main outcome of this trial is to prove that the ASO is safe and does not harm the individual. Clinical information is being collected to compare the progression of symptoms in this patient before and after treatment to determine if there are any improvements that could indicate that the ASO is working.

This clinical trial is possible because in the US there is a path established by the Food and Drug Administration (FDA) to develop new drugs for rare diseases that affect a very small number of people. While the FDA was the first regulatory agency to establish such framework, other countries are catching up. In the UK, a pilot consortium is establishing a pathway to identify and deliver experimental treatments to children with ultra-rare conditions. Find the press release here: <http://alturl.com/6xjqg>

While this trial is taking place in one person with DRPLA in the US, it is possible that more people from the US with DRPLA might be eligible for this experimental treatment. Ataxia UK and CureDRPLA are exploring with n-Lorem if people with DRPLA from other countries, like the UK, could also take part in an n-of-1 trial. The achievements and learning from n-of-1 trials in DRPLA, will not only benefit the DRPLA community. Other very rare ataxias which have a genetic cause and could be amenable to ASO treatments might be eligible for n-of-1 trials. While this initiative is very much in the early stages, Ataxia UK is proud to be pioneering in this field and will continue to provide updates to this community.



To stay up to date with the latest CureDRPLA developments, sign up to their newsletter here: <http://alturl.com/riqcn>

Prof Paola Giunti presents Wellbeing Week talk focusing on managing bladder symptoms in ataxias

As part of the Wellbeing Week 2024, the Ataxia UK services team hosted a talk on managing ataxia symptoms.

This was presented by Professor Paola Giunti, a specialist neurologist at the London Ataxia Centre. The talk was followed by an open Q&A. The session was well received; over 60 people attended, and many more watched the recording afterwards.

The main topic of the session, by popular request from questions sent in beforehand, was the management of symptoms of bladder dysfunction in ataxias. Bladder dysfunction is common in ataxias, including in those with multi-system atrophy (MSA), Spinocerebellar Ataxia Type-3 (SCA3) and Friedreich's ataxia (FA). The most common symptoms relate to problems with storage and include urinary urgency, frequency, and incontinence (overactive bladder symptoms).

To begin, Prof Giunti discussed that bladder overactivity can occur with ataxia, whereby bladder muscle contracts and releases urine more frequently or involuntarily. In some people with ataxia, bladder muscles can be overactive or underactive. Incomplete bladder emptying may result in recurrent urinary tract infections, but urinary tract infections may not be caused by ataxia.

Prof Giunti shared that antimuscarinic medicines are usually recommended as the first-line treatment for bladder dysfunction in ataxias, alongside bladder training and pelvic floor exercises. However, antimuscarinics are known to increase heart rate, so are cautioned in those with cardiomyopathy. There has been some research into the administration of Botox as an alternative treatment for those with bladder overactivity. She also shared the potential impact of a new treatment approach for bladder overactivity: stimulation to the tibial nerve (in the shinbone) - which communicates with the bladder.

Prof Giunti noted that these alternative methods of managing bladder symptoms in ataxias can come with risks, such as the need for a cystoscopy (insertion of a small camera into the bladder) to administer Botox and the need for repeated injections of Botox. She advised that anyone with ataxia who is experiencing bladder difficulties consult their GP. She emphasised that ataxia symptoms can differ from person to person. If you think you are experiencing bladder symptoms, it is important to share the Ataxia UK medical guidelines with your GP to work out which symptoms are caused by ataxia and which symptoms have a separate cause.

Watch the session recording here: <http://alturl.com/eduxq> or head over to the eShop section of our website to grab your copy of the **Ataxia UK Medical Guidelines**.



Rare Disease Day 2024

Tuesday 20th February 2024 marked Rare Disease Day (RDD), and together we highlighted how rare conditions are far more common than most people think.

There are 3.5 million people in the UK living with a rare condition, and 1 in 17 people will be affected by a rare condition at some point in their lives.

Rare Disease Day raises awareness for the 300 million people living with rare conditions around the world and their families and carers. Our Friends and supporters have kindly shared their stories and thoughts in support of this year's RDD campaign.

Here is what our friends, **Yvette** and **Vanessa**, said:

"I think it must feel lonely when you have anything wrong with you, but a rare condition which potentially shortens life expectancy, and stops you from doing the things most people take for granted is devastating.

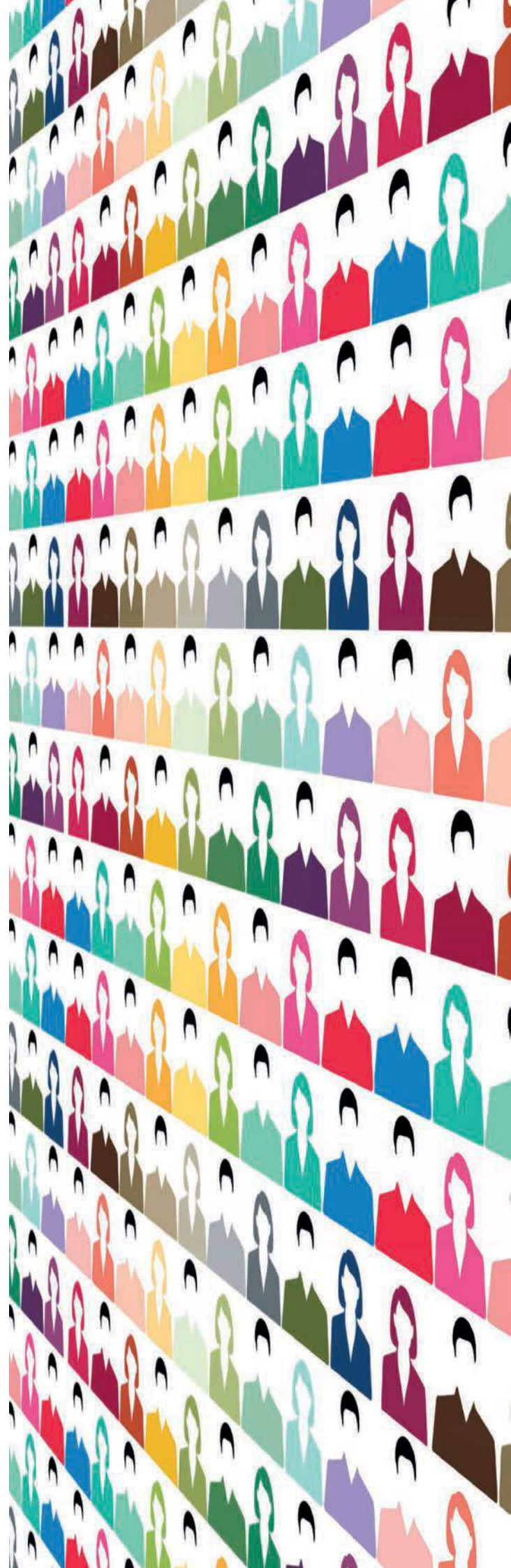
Yet the people I know living with a rare disease, when they meet with others with a similar condition, can be so optimistic and uplifting, it's a beautiful thing to see.

On rare disease day, I read somewhere: 'Alone we are rare, together we are strong'. I really believe that, so it is important to get the message across to the wider community, and Rare Disease Day is a great opportunity to do that."

Here is what our friend, **Haider**, said:

"10% of the global population live with a rare disease, and with 250 new rare diseases being discovered every year, rare diseases impact many lives globally. Isolation when living with a rare disease is very common, and it is important to keep the conversation going to raise awareness, so the required moral support, like I have through the Ataxia UK community, is readily available for those that need it."

We want to say a huge thank you to everyone who got involved and helped raise awareness. We would be grateful if our friends could be as supportive and enthusiastic for International Ataxia Awareness Day (IAAD), which is on September 25th, 2024. *To find out more, please contact communications@ataxia.org.uk*



All about autoimmune and gluten ataxia

AN OVERVIEW OF THE ATAXIAS:

Hi, I'm Carol, and I run the "Gluten Ataxia and Autoimmune" support group as a volunteer for Ataxia UK.

I am not a medical professional, but a person who had a diagnosis of 'possibly ataxia' desperate for answers and found out what I could about gluten ataxia.

There is a lot of information about gluten ataxia on the web, and some of it is misleading. Gluten ataxia is a progressive, autoimmune and neurological condition, similar in some aspects to most other ataxias. We aim to raise awareness of gluten ataxia and provide information to enable you to make an informed choice as to whether a gluten free diet is suitable for you.

Getting a full diagnosis can be a lengthy process. This journey leaves patients and families stressed and drained. The one thing that all types of ataxias have in common is the damage that is caused to the cerebellum. The cerebellum is the balance centre of the brain, positioned at the back and the bottom of the head. The main symptoms of ataxia are balance, fatigue, and speech problems. But there will be different degrees of how these symptoms effect individuals.

There can be other symptoms too as GA (Gluten Ataxia) is an autoimmune condition, but everyone is different:

- Painful, stiff, and aching legs, like you are having to drag them around.
- Migraines and headaches.
- You may or may not have digestive issues.
- Brain fog or a feeling of being 'spaced out'.
- Low mental health, irritable and unable to concentrate or multi-task.
- Peripheral neuropathy, which is pain, burning sensations and tingling in your extremities.
- Vision problems.
- Generally feeling unwell.
- Other allergies or sensitivities.
- Dizziness.

There are three ataxia clinics in the UK. The UCLH at Queen's Square in London led by Professor Giunti and her team that mostly specialise in the hereditary and genetic types of ataxias, and the Sheffield Royal Hallamshire Hospital clinic run by Professor Hadjivassiliou and his team that mostly are associated with gluten ataxia and the autoimmune ataxias. Also, the Oxford Ataxia Clinic at the John Radcliffe Hospital.

If you think you might have gluten ataxia, which is progressive then time is critical. Speak to your doctor or neurologist and get a referral.

In the next article we will be looking at the tests unique to the Sheffield Hospital that are used for a positive diagnosis of gluten ataxia and autoimmune ataxia.



*If you need information, advice or support, please contact the Helpline by phone to **0800 995 6037** or by emailing help@ataxia.org.uk The Helpline is open Monday to Thursday, 10.30am to 2.30pm.*

The Importance of Giving

This likely isn't the first time we have reached out to you about the importance of regular giving, and that's because the importance of committed regular givers, particularly to a small charity like ours, can't be overstated.

Supporting Ataxia UK with a regular gift ensures those affected by ataxia continue to receive support to help manage their diagnosis. Your regular gift is a way to give back and help others who need additional assistance in managing their ataxia symptoms. *If you would like to know more about the significance of regular giving and how it impacts our service users then reach out to **Kieran** at fundraising@ataxia.org.uk*

Though, if you do need another reason to come on board as a regular giver then you should hear it from our wonderful friend **Gemma**. As Gemma says: *"Funding is so important, not only to keep the current support services that Ataxia UK give, but also to expand them. I like to think that in some small way I'm helping with that. It's so easy to set up and it means I don't have to think about giving a donation, I'm already doing it."*

Not only is Gemma an active fundraiser, but she is also a volunteer here at Ataxia UK which offers some insights into the running and ongoings of the charity. *"Regular giving allows for Ataxia UK to plan by giving them an idea of what their income is likely to be in a given year. This ensures good forward planning for the charity allowing them to fund a particular service or research for a set period of time."*

Because this isn't the first time we have shared information about the importance of regular giving, you or a family member may already have an active direct debit or standing order supporting those affected by ataxia. We want to take every opportunity possible to thank you for your ongoing support and commitment. We know it is around this time of year that many supporters evaluate their financial situations and for those of you who are in the position to give more and would like to increase their regular gift – *drop the fundraising team an email on fundraising@ataxia.org.uk for more information on how to do this.*

Chance2Win

Our Chance2Win fundraiser is a unique opportunity to give back to the ataxia community while also being in with the chance of winning one of three top cash prizes every quarter, with the top prize of £500!

To join the Chance2Win lottery you need to purchase tickets which cost £2 each. You can purchase tickets either on a monthly, quarterly or annual basis – whichever is most convenient to you! *You can do so either on our website: www.ataxia.org.uk/chance2win or ring us on **020 7582 1444**.*

Those who take part in the Chance2Win lottery and have won, know it is a great way to support those affected by ataxia – but with the anticipation every three months of receiving a call or an email being notified about winning that £500 cash prize!



Calling all superheroes!

SUPERHERO TRI (POWERED BY MARVEL)

17th August 2024 | Dorney Lake, Windsor (Winter: 1 Dec)

Join an exhilarating event where Superheroes with disabilities lead the way, with no cut-off times and all gadgets welcome! Team up with Sidekicks for an unforgettable experience, plus meet Marvel heroes and celebrities in a day full of fun and inspiration!

As an official charity Friend of the Superhero Series – **the UK's one & only disability sports series** – we're asking our own community of Superheroes & trusty Sidekicks to grab your capes & join us! Choose your challenge: Get your relay team together for one of three tri distances: 150m swim; 3km cycle; & 1km push/run. There's also limited places for the **1km Superhero Charge!**

Anyone can join the fun as long as at least one person per team considers themselves to have a disability (of any kind). Come with your team fully formed or let us team you up! Enjoy free sports, entertainment, and parking at Superhero Village—bring friends to cheer on the teams! *For more on this & other Superhero missions contact our team at fundraising@ataxia.org.uk*

ULTRA CHALLENGE®

Walk, jog, or run the best of Britain! With 'continuous' full 100 km challenges or a 2 day 'daylight' 100 km option with camping at halfway, a new 75 km '3/4' choice, testing 50 km, Half & 25 km Quarter distance options, a couple of engaging off-road marathons, and a few 10K 'taster' events – there's an Ultra Challenge® for everyone! *To sign up and receive a free running vest or t-shirt and your supporter pack, contact our fundraising team now fundraising@ataxia.org.uk*

ATAXIA CLASSIC 2024

The charm of Kilnwick Percy Golf Club awaits cyclists and their families this year on 22nd September! Yes, we are back at this amazing venue for this year's much awaited cycling event in the beautiful countryside of Yorkshire!

Sign up now for an exclusive cycling vest, water bottle, and fundraising pack and outstanding support! For more information or to sign up, email us at fundraising@ataxia.org.uk or visit <http://alturl.com/md8e3>

GREAT NORTH RUN 2024

Join #TeamAtaxiaUK for the Great North Run on 8th September 2024!

The world's biggest and best half marathon, with 60,000 runners taking on the 13.1-mile route from Newcastle to South Shields each year. This iconic event is a once in a lifetime opportunity! *To sign up and receive a free running vest and your supporter pack, contact our fundraising team fundraising@ataxia.org.uk*



Fundraising thank-yous

There are so many supporters, and it is impossible to name them all here, but here is a random selection of superheroes, who went above & beyond to support the ataxia community.

A huge congratulations to **Rev Lynn Rees (1)** and the congregation at St John's Church Penrhyncoch for raising an amazing £430 during a coffee morning to support Ataxia UK! Thank you for your support.

Brooke Shotton (2) & her Music Club held a piano concert to raise money for Ataxia UK. Her cousin Rebekah has ataxia and she wanted to raise awareness and funds to support the cause. The concert raised an amazing £380! Thank you, Brooke & the team.

Ataxia superheroes **Angela Sampson & Holly Kiely (3)** took part in the Hyrox Madrid doubles competition in March! They were inspired by their friend **Cassie** who has ataxia and have raised a fantastic £1270.88 inc. Gift Aid to support the ataxia community! Thank you to you both!

The incredible **Jennifer Cooke (4)** has completed her amazing water walk & raised a phenomenal £3080.50 inc. Gift Aid! Thank you so much Jennifer, and thanks to all your supporters for this amazing achievement. Well done.

Will Street (5) has donated £80 which is the latest in his regular support for Ataxia UK from sales of his specialist adapted wheelchairs! Thank you, Will, for your continued support and we wish you a prosperous year! Check out his shop here: www.willstreetwf.com/shop

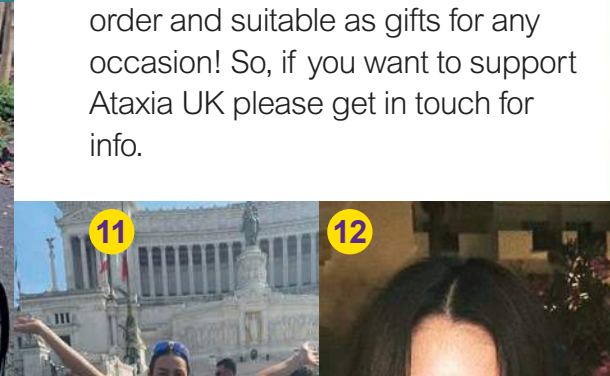
A 'Coffee Concert' at St Edward's Church in Cardiff saw a full house listening to **Women in Harmony & Voice Male (6)**, raising money for people living with ataxia and supporting Ataxia UK with an amazing £481.52 raised! Thank you so much for your support.

A huge shout out to **Sian Smith, daughter Ffion (7)** and **family!** They threw a wonderful garden party in support of Ataxia UK's vital work and raised an amazing £220. It sure was a blooming success and a fun-filled day. Amazing heroes - well done!

Nicole (Nicky) Beck (8) is an ataxia hero, taking part in her first white collar boxing match to raise money for Ataxia UK. She had never boxed in her life but wanted to raise as much money and awareness as possible for ataxia after her mum was recently diagnosed. What an absolute legend stepping into the ring for such a great cause. She raised a smashing £660 inc. Gift Aid. Thank you and your family for this amazing achievement!

A massive round of applause goes to **Emily Harrison (9)** who conquered the mighty Snowdonia mountains in memory of her friend **Scarlett**. Every step Emily took on her marathon hike helps to make a difference to the lives of those living with ataxia. Thanks to her amazing effort, she has raised £2269.02 inc. Gift Aid!

Thank you and congratulations **Lena De Greef (10)** on your amazing run at the Paris Half in support of #ataxia communities. You smashed your own fundraising target and raised a whopping £2454.75 inc. Gift Aid! Well done.



Adele Gerry (11) absolutely smashed it on her first ever marathon! Tackling the blazing streets of Rome in loving memory of her father, **Mark**, who sadly passed away from ataxia in 2017. Raising over £800 - such an incredible feat! We are all so proud of you!

Melissa Wright (12) raised an amazing £512.50 inc. Gift Aid in her 4-mile walk to raise awareness of ataxia! Thank you, Melissa, you are an extraordinary ataxia hero!

Congratulations to **Roots Fitness (13)** on your first anniversary! They celebrated 1 year of operations by holding a charity event raising money for Ataxia UK! Thank you, Roots Fitness, and all your members and supporters for raising an amazing £210. We wish you a prosperous and successful future.

A huge thanks to **Andrea Stephens (14)** for raising a whopping £450 from her Tinsel Hedgehogs sales!

Thank you so much for all your hard work and supporting ataxia communities every year! These lovely hedgehogs can be made to order and suitable as gifts for any occasion! So, if you want to support Ataxia UK please get in touch for info.

Lucky to be loved

Here is fantastic blog post from our wonderful Friend, Tallulah. She talks about love and self-worth. As she puts it, “I talk about my own preconceptions, my internalized ableism and the hurtful assumption that the disabled community cannot have loving and meaningful connections”.

Like many young girls I fantasized about falling in love, about meeting the right person who just completely gets me. Growing together, buying a house together, the big white wedding and starting our own little family. My teenage years were spent creating mood boards on Pinterest, pinning my favourite wedding venues, the aesthetic for my future home and wondering what this mystery person who would walk into my life would be like.

But when I was diagnosed my dreams were shattered, I spent countless hours in therapy grieving the fact, which I thought to be undeniably true, that ‘no one is going to want me now’. That was my internalized ableism. I thought I was broken, and who’s going to want that?

It’s been just shy of 10 years where I’ve been working on changing this thought pattern, I’ve met so many amazing people who have taught me that I am worthy of friendships, a romantic relationship and so much more. I’m eternally grateful to all these wonderful individuals - although I’d like to think they feel the same way about me.

I’ve really tried to fight this omnipresent niggling feeling yet it is still there. Some days more than others, just lingering in my subconscious.

The feeling I’ve so often mentioned in other posts, am I worthy? Do others see me as a burden holding them back? Over the past year I’ve really learnt to value what I can offer. Gradually that pie chart of what makes me me has become a little bigger. I am kind, empathetic (sometimes too much), generous, tolerant, and considerate. I’d also rate myself a solid 7.5/10.

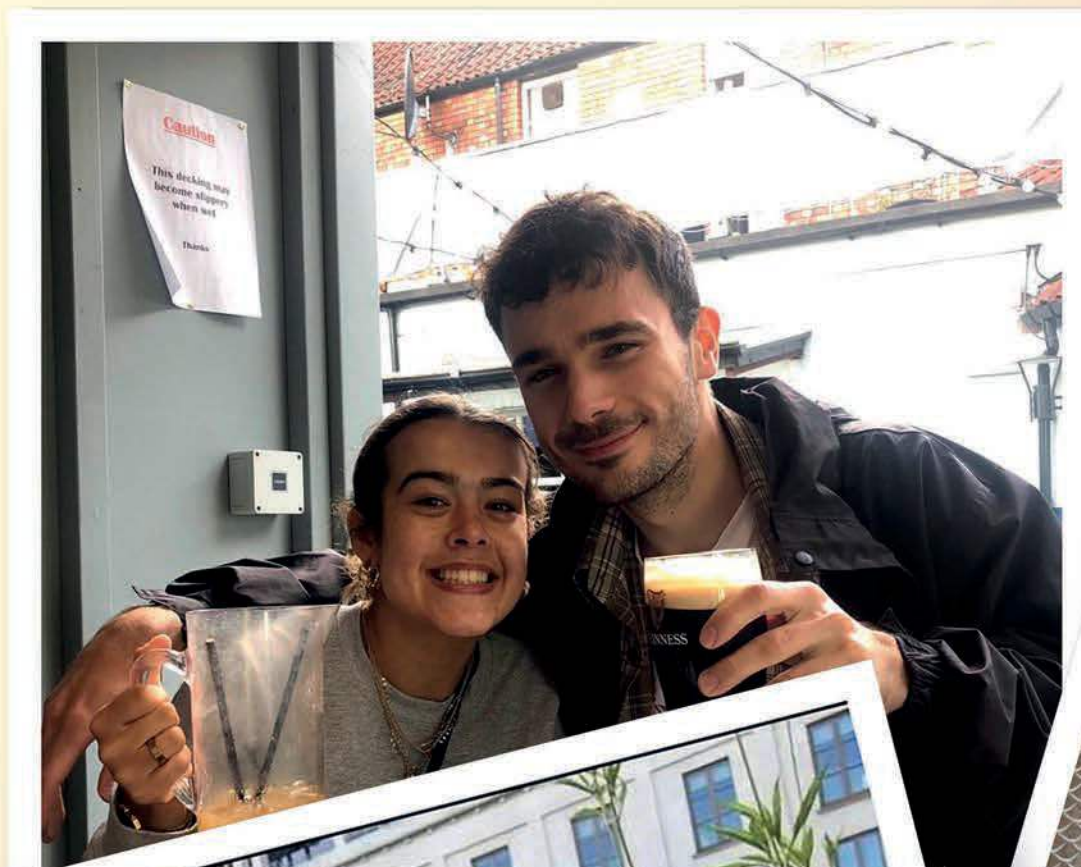
But frequently, I ask myself, is that enough? Am I lucky to be loved?

It may, or may not, come as a shock that my partner gets a lot of credit for being with someone like me. For being there for me through thick and thin, for not running a mile when shit hits the fan. Because even after 6 years he clearly is the only one in this relationship who has anything worth contributing. I do feel lucky to be loved by someone so kind, so caring and so considerate but I reckon, and he reminds me often, that he’s pretty lucky too.

But after getting reminded, almost on a monthly basis, of how lucky I am to have found someone who loves me for me, it starts to knock my confidence. Those insecurities and soul crushing feelings creep back, but this time to the very forefront of my mind. Everywhere we go the devil on my shoulder informs me that everyone is thinking the same thing. How and why on earth is he with her?

Brushing off these feelings of inadequacy is easier said than done. Just when I feel at the peak of my confidence, someone will look at us or say something that makes me wonder if it’s true. Am I lucky to be loved?

This post is for anyone else who feels this way because I am certain you’re out there, you are enough, you are worthy, and you are so so so much more than your illness/disability physical or mental. We are all lucky to be loved and to love but we also deserve to be ADORED, please don’t forget that.



I have ataxia, but ataxia doesn't have me

Our friend, Laura, has kindly shared her ataxia journey with us and wrote a little about the importance of acceptance.

Hi, I'm Laura. I'm 19 and in my first year of university, studying psychology. I was diagnosed two years ago with familial Cerebellar ataxia. I didn't truly realise how difficult it is to live with ataxia until I developed it at 16 and my body was replaced with a new one. I'd grown up knowing about ataxia as my dad also has cerebellar ataxia. He's the bravest person I know, but I never thought I'd have ataxia and have to be brave like him. Until 8 months ago, I thought ataxia ruined my life, but it hasn't, life is simply different.

I love swimming; it's my relaxation as well as exercise. I do Pilates most weeks and go to the gym. I went on a climbing wall recently, and I'd love to do it again sometime! I also enjoy going for walks. Fatigue makes it difficult to go for long walks, but I enjoy them. I also enjoy baking, as well as art and being creative. Spending time with my family and friends is my absolute favourite thing; I also love animals (especially my pets).

Ataxia can make it difficult to do things I enjoy, on days when I cannot do very much, I have incredibly supportive friends and family who are happy to stay in and watch a film with me or something instead of going out. Very few people understand how hard it is to navigate living with ataxia, and even fewer understand that it's something that affects you every second of your life – it isn't something you can just turn off for a bit. Developing ataxia is really like learning to live with a new body – one that hurts and is tired all the time, one that suddenly struggles to do so many simple things, and one that no longer runs, jumps, and does all the things that you used to enjoy doing.

What happens in the future happens, and you cannot go back and change the past, don't miss out on life because of what you previously could have done differently or your fear of the future. For too long, I feared anyone knowing that I had ataxia, so I would never ask for help. It's still scary, but I'm slowly getting better at asking for help, and it makes life a lot easier.

Balancing ataxia with living life how I want sometimes seems impossible, but I'm trying to learn to listen to my body and let myself rest when I need it.

I had incredible support in sixth form, and I was given so much advice that I would not take it at the time – I decided it would not work before even trying. I cannot thank those people enough for everything they did for me. Now I'm taking that advice, and I wish I had sooner.

I've now realised that this sudden moment when I know exactly how to live with ataxia doesn't exist. Acceptance and learning to manage it come in small steps, not a huge leap. Writing this, a part of me is thinking, who am I to be talking about acceptance? I've hardly figured it all out. I'm already several steps higher than I was a few months ago. I wish I could go back a couple of years and tell myself that life is not over.

Learning to accept having an incurable condition that's incredibly rare is something that no one can really teach you. However, I know that I am so much more than just ataxia, just because I have ataxia, it doesn't mean that ataxia has me.



My pet and me

After the amazing presentation about assistance dogs from Dogs for Good at our Annual Conference in October 2023, we thought it would be interesting to hear from the ataxia community about what benefits and support they gain from their pets. In the last issue, we featured Dawn and her trusty rottweiler. In this issue, our volunteer Emma talks about her cat, Maggie.

Last night I fell asleep while she was cuddling my knee. Sometimes I wake up in the middle of the night and she is sitting on my ribs, staring at my face. I read somewhere that cats do not fully sleep as a survival mechanism, part of their brain is always awake so when a human sleeps, it is possible that a cat would think that you are dying. This would also explain why on occasion, I wake up to find that Maggie has placed feathers around my head like some kind of death shroud!

Maggie is a 3-year-old, water coloured calico cat. Maggie is narcissistic and annoying. She is extremely vocal, which has earned her the nickname of the talking cat. She cries for food even when she has some, had a fight with the cat next door and he lost an eye, and the other day she made her first attempt to catch a Kite (big predatory bird 3 times her size) leaving me both horrified and a little proud! She is a warrior queen.

Maggie is my companion. Even now she is next to me while I am writing. She shows concern if I am feeling anxious and doesn't like it when I go out. Maggie brings me a feather when she wants some Dreamies and gives me comfort just by being in the room. Maggie accepts me, completely, just for who I am. She does not care if I am having a bad day (as long as she is fed!), she doesn't care what I am wearing (as long as she can cuddle) and she will not judge.

I would not want to be without her. She is an outdoor cat, so she is free to go out and be wherever she wants to be, but she chooses to be in here with me so maybe she feels the same way.

Have you got a pet that helps you cope with your ataxia? We want to hear from you! Contact our team at communications@ataxia.org.uk to share your story.



Celebrating Carers Week

As Carers' Week (10-16 June) approaches, Ataxia UK celebrates the invaluable contributions of unpaid Carers within the ataxia community. We pay tribute to those who selflessly devote their time and energy to caring for their loved ones, navigating the challenges of illness and disability with unwavering dedication.

WHO EXACTLY ARE UNPAID CARERS?

They are the unsung heroes among us – friends or family members who provide essential support without monetary compensation. Their responsibilities may vary, from assisting with personal care to managing household chores, administering medication, or accompanying their loved ones to medical appointments. Some carers provide round-the-clock care, while others offer remote support, adapting to the unique needs of their loved ones.

The support provided by unpaid carers extends far beyond physical tasks. It encompasses emotional support, companionship, and a reassuring presence for those they care for. However, despite the rewarding aspects of caregiving, many carers find themselves in need of support themselves. They may require practical assistance in their caregiving role, respite care to take much-needed breaks, financial guidance, or emotional and wellbeing support to navigate the challenges they face.

Balancing caregiving responsibilities with employment can be a daunting task, often forcing carers to make difficult choices. Many have had to leave their jobs, impacting their financial stability and confidence. However, carers have rights in the workplace, including the ability to request flexible working arrangements and time off for emergencies involving dependents. Some employers offer additional benefits and support, such as carer's leave, recognising the importance of supporting employees with caring responsibilities. For those who are not working or are on a low income, various benefits may be available to alleviate financial strain, including Carer's Allowance and Universal Credit.

In celebration of Carers' Week, Ataxia UK is hosting a Chair Pilates session on Tuesday 11th June, offering carers an opportunity to rejuvenate their bodies and minds. Led by Sonia Forde this session provides a gentle yet effective form of exercise, tailored to accommodate individuals with varying mobility levels. It serves as a reminder to carers to prioritise their own wellbeing amidst their caregiving responsibilities.

Sign up here: <http://alturl.com/fuydh>

There is also a **Carers' Support Group which meets regularly online** to offer support and a space to connect with and share experiences with other Carers from the ataxia community. The next Carers Support Group meeting will be on Thursday 13th June at 14:00-15:30.

Register today at: <http://alturl.com/887r8>

For more information about the Carers' Support Group and our other support groups please visit the Ataxia UK website <http://alturl.com/5zy6t>



Carers UK offers a range of advice and information on all aspects of Caring and you can find their factsheets here:

<http://alturl.com/6q9ys>

If you are a carer and require support in your caring role, please contact the Ataxia UK Helpline on 0800 995 6037 or by email to help@ataxia.org.uk

Happy Volunteers Week!

Our annual Volunteers Week is taking place between the 3rd and 9th of June. With hundreds of charities being involved, it's the perfect opportunity to come together to recognise, celebrate and showcase volunteers in all they contribute to our local communities, the voluntary sector, and society as a whole.

Since 2020 we have recruited and supported over 100 volunteers spread across the UK. Our volunteers have helped in so many areas, from leading the vital support groups, to assisting those newly diagnosed with ataxia at ataxia clinics. Throughout these roles, our volunteers have shown an unwavering passion for helping to develop and deliver our services.

Many service users who contact Ataxia UK are isolated or struggling with their new diagnosis. In giving peer support, information, friendship & a listening ear to our service users, volunteers provide light to people who were struggling in the dark. In this way, the work of volunteers has been astounding and vital in helping the ataxia community. This year, in celebration, we are hosting a variety of events for volunteers which will be advertised on website soon.

We cannot overstate how grateful we are for your ongoing contributions and the dedication you have in giving up your time to help others. We couldn't do this work without you, and so from all of us here at Ataxia UK & on behalf of the ataxia community. Thank you, the services team.

There are a variety of volunteer roles available at Ataxia UK, including the Helpline volunteer role (See p23). We're always looking for people who are willing to take on these roles with the same passion, peer support and friendliness we see from our current volunteers.

To find out more about the roles we have available, as well as how you can get started with volunteering with us, please see our webpage here: <http://alturl.com/jhz3u> or email volunteering@ataxia.org.uk

If you need information, advice or support, please contact the Helpline by phone on 0800 995 6037 or by emailing help@ataxia.org.uk The Helpline is open Monday to Thursday, 10.30am to 2.30pm.



How the Helpline helps

Getting an ataxia diagnosis can leave people feeling bewildered and quite often with very little information on ataxia - if any. Often told by General Practitioners (GPs) that there's no cure or treatment so you're just going to have to get on with it. This leads people to do their own research that leads them to the Ataxia UK website and our Helpline.

The Helpline is often the first place that people feel listened to and understood and at the end of the phone calls we often hear *"it's just so reassuring to know that you are there, and I am not alone, it's made the world of difference to me"*.

This is best highlighted through some of the personal stories we encounter on the Helpline. The story below is about Rosemary who contacted Ataxia UK last year.

Rosemary's journey with the Helpline shows the varied ways we can help. Rosemary contacted us after her diagnosis of ataxia, it was a long journey to get to the diagnosis, having seen 2 different neurologists and then going privately for her final consultations, it still took nearly 3 years. When Rosemary did finally get her diagnosis, she was left feeling that she didn't know where to go or how to move forward being left with the only advice to keep active, both mentally and physically.

Rosemary has said that Ataxia UK's advice about pacing yourself and not getting too tired or fatigued, helped her more than any other advice.

Rosemary called the Helpline to see how we could help and in the initial conversation, we let her know how Ataxia UK could help through support services such as the All About Ataxia sessions that we run for the newly diagnosed and their families, as well as our local support groups and specialised ataxia centres. We arranged for Rosemary's closest support group leader to give her a call. Rosemary was concerned that her GP didn't really understand what ataxia is, so we agreed to send them our Medical Guidelines. With the information that the Helpline had given her about the London Ataxia Centre Rosemary was able to get her GP to make a referral to the Centre and she has an appointment coming up soon.

When contacting the Helpline again Rosemary spoke to another member of the team who talked her through the benefits that she might be eligible for – a couple of months later, Rosemary contacted us to say thank you as she was now in receipt of Attendance Allowance and a Blue Badge – which is great news!

Rosemary got in touch with the Helpline again since she wanted to join some of the sessions that we were running for Wellbeing Week, but she was concerned that she would struggle to use Zoom as she didn't feel very tech-savvy. Rosemary is in her

early 80s and Zoom was relatively new to her. To help give Rosemary the knowledge and confidence to be able to join the sessions, we set up a trial Zoom meeting to iron out any issues that she might have. We then suggested that she contact Ability Net (charity that supports older or disabled people to use technology) who could hopefully send out a volunteer to teach Rosemary face-to-face as it's much easier to learn with someone with you.

Rosemary knows that any time she has a question or needs some support she can call us.

WANT TO JOIN THE HELPLINE TEAM?

The Helpline is run by staff and wonderful volunteers that cover our opening hours. Without volunteers we would not be able to run the service or reach as many people as we do.

We are hoping to recruit more volunteers to join us on the Helpline to aid more people like Rosemary. We are looking for people who can commit to at least one 2-hour Helpline shift a week between the hours of 10:30 and 2:30, Monday to Thursday.

Basic IT skills, including use of email and the internet (and databases if possible!) as we work remotely. We will provide you with support and training along the way.

There are lots of different tasks to do on the Helpline, like signing up new Friends on our database, responding to emails or taking calls. We don't expect our volunteers to do all those things – though they can if they want to!

If you need information, advice or support, please contact the Helpline by phone to 0800 995 6037 or by emailing help@ataxia.org.uk

Volunteering on the Helpline is a great way to learn new skills and information that could help you in the future.

This is what one of our volunteers had to say about the Helpline:

"I've been on the Helpline for 7 months now. The support and training I have had from Jess and Wendy has been excellent. You are never alone in dealing with queries. We have, as a family, been living with ataxia for over 10 years, and so have lived experience, but everyone has a different lived experience that is useful to people accessing the Helpline. It is a feeling to help others and we need more people to use their lived experience in this way. I have also learnt so much that helps my family, so I would not hesitate in contacting volunteering and see how you can help the ataxia community of which we are part of."

If you are interested in joining our Helpline team to support the ataxia community then please contact us at volunteering@ataxia.org.uk



Thank you
to everyone
who has given
a donation
in memory of
a loved one

Leaving a legacy
is one of the most enduring ways
to make an impact

Much of our research
has been made possible
by the foresight and generosity
of our Friends and supporters
who have remembered our work
when making their will

We currently have several
research projects underway,
some of which are funded,
at least in part, by gifts left to us.

Your legacy can be hope for the future